Associations Between Engagement in the Patient-Provider Relationship and Quality of Life and Adherence Among Persons Living with HIV/AIDS

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Abstract

Purpose: This cross-sectional, correlational study was conducted to examine the associations between engagement in the patient-provider relationship and quality of life and adherence among persons living with HIV/AIDS. The project is a sub-study of an international, multi-site study examining the adequacy of a self-care symptom management model that hypothesizes relationships among person, illness representation, symptom self-care, perceived effectiveness of self-care activities, adherence, and outcomes appraisal in a large, HIV-positive sample (*n*=1072). **Method:** A convenience sample of non-hospitalized persons receiving care at The Ohio State University Infectious Diseases Outpatient Clinic and Children's Hospital Family AIDS Clinic and Educational Services was recruited from May to November, 2003. IRB approval was obtained from each of the participating sites. A 35-page survey was administered to subjects qualifying for the study who provided informed consent. Subjects received $20 for completing the questionnaire. All measures were self-report. Demographic data gathered included gender, age, race/ethnicity, length of HIV diagnosis, and presence of AIDS diagnosis. The sample included 57 persons living with HIV/AIDS with a mean age of 40 years, of which 28% were women and 58% were white; the mean length of HIV diagnosis was 10 years and 39% had an AIDS diagnosis. Engagement was measured using the 13-item *Engagement with Health Care Provider* scale. The *HIV/AIDS Targeted-Quality of Life* scale, a 42-item HIV-specific instrument, was used to measure the following nine dimensions of quality of life: overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust, and sexual function. Adherence, an assessment of compliance with provider advice and medication regimen, was measured with the 5-item *Advice and Instruction* scale and the 15-item *AIDS Clinical Trials Group (ACTG) Reasons for Nonadherence to Medications* checklist, respectively. **Findings:** Better quality of life was found to be significantly related to engagement with health care provider (*p*=0.013) as was adherence to provider advice (*p*=0.001). While positively correlated, no statistically significant relationship was found between

engagement and adherence to medication. **Implications:** Results of this study support existing literature suggesting a positive association between increased engagement with health care provider and better quality of life among persons living with HIV/AIDS. A limitation of the study, particularly in regard to adherence, is the self-report design. Nevertheless, the study does suggest the need to develop and promote strategies that foster a healthy patient-provider relationship in this population to improve quality of life and adherence to treatment.

Associations Between Engagement in the Patient-Provider Relationship and Quality of Life and Adherence Among Persons Living with HIV/AIDS

The HIV/AIDS epidemic has had devastating effects on American society since its beginning in the 1980s. According to reports from the Centers for Disease Control and Prevention (www.cdc.gov, n.d.), between 800,000-900,000 people are currently living with HIV/AIDS in the United States, with 40,000 new cases diagnosed each year. As of December 2000, there have been 448,860 AIDS-related deaths. These statistics may well be an underestimation of the problem, as they do not represent unreported cases.

HIV/AIDS presents countless challenges to those suffering from the disease. Complex medication schedules with adverse side effects (Reynolds, Neidig & Brashers, 1999), negative social stigmas (Robinson, 1998), and the eventual decline in immune function are just a few of the challenges faced by people living with HIV/AIDS. However, with the advent and relative success of antiretroviral (ARV) therapy in the mid-late 1990s, more people infected with HIV are living longer, healthier lives (Roberts, 2002). Active self-management is necessary for the patient to actualize the benefits of adherence to therapeutic regimens. Furthermore, the importance of quality of life becomes more salient to patients realizing that they have a chronic disease to manage for what could be a relatively long life (Holzemer, Spicer, Wilson, Kemppainen & Coleman, 1998).

As a result of advancements in treatment, HIV/AIDS has evolved from a lethal disease to a chronic one that requires regular interaction between patient and health care provider (Vogl et al., 1999). The literature suggests that the nature of the patient-provider relationship plays a role in patient outcomes among people living with HIV/AIDS. Because health care providers were not immune to the extreme negative social stigma associated with HIV/AIDS at the onset of the epidemic, many nurses experienced fear of becoming infected (Burr, 1996; Peate, 1995) and homophobia (Rose, 1994; Taylor & Robertson, 1994), feelings that consequently affected the

care they provided (van Wissen & Woodman, 1994). Such feelings by the health care provider were often short-lived as prognosis for the disease was poor and death directly imminent. However, the increased life expectancy of HIV/AIDS patients warrants health care workers to be more involved in the care of these patients for longer periods of time, thereby making the relationship even more critical in patient outcomes (Ickovics & Meisler, 1997; Singh, Squier, Sivek, Wagener, Nguyen & Yu, 1996).

The ramifications of the change in the disease affect both patients and providers, as well as the interaction between the two. The nature of the interaction can result in greater patient satisfaction and adherence or have the reverse effect, depending on how patients perceive the interaction (Roberts, 2002). Moreover, providers are faced with providing long-term care for a socially stigmatized population, while patients must manage a complex disease in addition to coping with social stigmas. Research is needed to examine the extent of these ramifications on patient outcomes as they relate to adherence and quality of life in people living with HIV/AIDS.

Review of Literature

Adherence

The research related to adherence to therapeutic regimens in HIV/AIDS patients has been extensive. Much of this research addresses adherence to ARV medications.

The benefits of ARV medications are remarkable in their effect on the progression of HIV. If taken correctly, ARV medications have the potential to reduce viral load below the level of detection in some patients; in turn, there is the possibility of slow recovery of immune function (Holzemer et al., 1999; McPherson-Baker, Malow, Penedo, Jones, Schneiderman & Klimas, 2000). Conversely, non-adherence is dangerous because the patient can potentially develop resistance to ARV medications. Recent evidence suggests that even 80% adherence to ARV therapy can lead to resistance (Holzemer et al., 1999). Further, Blaschke (1997) found evidence of increasing viral load after patients missed only two days of medication.

Reports of non-adherence to ARV medications vary across studies. A cross-sectional study of 52 HIV-positive men and women found that 58% were non-adherent to their prescribed regimens (Muma, Ross, Parcel & Pollard, 1995). A similar study reported that 50% of participants were non-adherent (Chow, Chin, Fong & Bendayan, 1993). Further reports have suggested a range of adherence from 20-80% among various populations (Chesney, 1997).

The literature supports an interplay of numerous variables in adherence among HIV/AIDS patients. Holzemer et al. (1999) identified forgetfulness, lack of information, symptom side effects, treatment fatigue, and lack of social support as a few of the variables leading to poor adherence.

The presence of distressing symptoms is a correlate of non-adherence that has been identified by several researchers. Fontaine and colleagues (1999) conducted a multicenter, cross-sectional study of 118 hospitalized and 172 ambulatory HIV patients and their physicians in France to assess physicians' reported recognition of symptoms reported by patients. Fatigue was the symptom most often identified by both hospitalized and ambulatory patients at 77% and

72% respectively. Sleep problems and anxiety were also highly reported with 62% and 51% of hospitalized and ambulatory patients reporting sleep problems respectively, and 64% and 63% of hospitalized and ambulatory patients reporting anxiety respectively.

Other research suggests that much of the intolerance to ARV therapy is due to treatment-related symptoms (Melbourne, Abbaticola, Rana & Fisher, 1998). Of the 74 HIV-positive patients in this study, 32 reported intolerance as the primary reason (81%) for discontinuing their medication. Those who were intolerant had significantly higher incidences of the following symptoms than the tolerant group: nausea, 73% vs. 30%; vomiting, 50% vs.14%; and diarrhea, 54% vs. 46%.

Holzemer et al. (1999) examined the relationships between the five dimensions of a health-related quality of life model and self-reported adherence to medication, provider advice, and medical appointments in people living with HIV. A convenience sample (*n*=420) of HIV-infected men and women recruited from seven cities across the United States yielded results of higher symptom scores, particularly depression, being correlated with increased likelihood of non-adherence to medication, provider advice, and to miss health-related appointments.

These studies illustrate the importance of adherence in managing and controlling HIV/AIDS. Moreover, they lend support to the necessity of first identifying factors that contribute to non-adherence in order to implement the most beneficial interventions to promote adherence.

Quality of Life

Quality of life encompasses numerous facets of life and has been defined as a "multidimensional construct" (Vogl et al., 1999, p.254). The success of ARV medication also has implications for quality of life issues in people living with HIV/AIDS. Further, quality of life has become of greater concern with the growing acceptance of HIV/AIDS as a chronic disease.

The presence of symptoms related to the disease and its treatment has been proposed as the strongest indicator of impaired global quality of life in HIV-positive patients (Wachtel, Piette, Mor, Stein, Fleishman & Carpenter, 1992). In a sample of 42 HIV-infected women,

Israelski and colleagues (1998) found that greater total number of HIV symptoms was associated with decreased quality of life. Wachtel and colleagues (1992) found that in a sample of 520 HIV-infected patients, 72% reported neurological symptoms, 69% reported constitutional symptoms, 50% reported dyspnea, and 47% reported diarrhea. The presence of multiple symptoms was correlated with a lower quality of life in this study.

Other studies have focused on determining what factors truly represent quality of life in HIV/AIDS patients. The Living with HIV scale was developed to measure the quality of life of people living with HIV/AIDS (Holzemer et al., 1998). This 38-item scale was developed from the grounded theory, Salvaging Quality of Life (Wilson, Hutchinson & Holzemer, 1997). The theory was generated from interviews with a sample of Hispanic, Anglo-American, and African-Americans (*n*=38) and family/significant-other caregivers (*n*=10) and from six focus groups with expert nurse clinicians in the field of HIV/AIDS care (*n*=30). The instrument identifies the following nine domains of quality of life: avoiding the fear zone, loss, body image, juggling treatments and side effects, independence, death calculations, cherishing the environment, coveting time, and resolving spiritual issues. Using this scale, Holzemer et al. (1999) found that patients who viewed themselves positively on cherishing the environment also reported greater adherence and were more likely to follow advice.

Similar to the Living with HIV scale, the HIV/AIDS Targeted- Quality of Life instrument (HAT-QoL) identifies nine dimensions of quality of life: overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust, and sexual function (Holmes & Shea, 1998). Again, item content for this 42-item instrument was determined from interviews with a sample of HIV-positive individuals (*n*=243).

Research on quality of life in people living with HIV/AIDS is often problematic as a standardized measurement still eludes researchers. However, the research to date suggests that a variety of physical, psychological, and social factors must all be considered when addressing quality of life issues.

Patient-Provider Relationship

As with other chronic diseases, the patient-provider relationship plays a critical role in patient outcome within the HIV/AIDS population (Bakken et al., 2000; McPherson-Baker et al., 2000; Pearson & Raeke, 2000). According to Robinson (1998), patient satisfaction with health care is a primary outcome measure of quality of care.

Kelly and colleagues (1988) reported that nurses, as members of society, cannot avoid being swayed by the social issues that affect public attitudes towards HIV/AIDS. Negative attitudes towards people with HIV/AIDS may affect the quality of patient care or even result in refusal to care for these patients (Frank, 1986; Gerbert, Macguire, Badner, Altman & Stone, 1988). Those who do reluctantly care for HIV/AIDS patients often cause the patient to act defensively and be uncooperative. Kemppainen and colleagues (1998), in a qualitative study of 118 men and women with HIV/AIDS, noted that patients' behaviors were directly related to the nurse-patient interaction. Meaning, if patients perceived their nurse as disrespectful, they would reciprocate the disrespect toward the nurse. In this regard, the nature of the interaction between patient and provider becomes critical in maintaining a trusting environment.

Furthermore, the patient-provider relationship has been proposed as an important factor in adherence. Holzemer et al. (1999) found that in an HIV-positive sample, patients with more engagement with providers were more likely to follow the provider's advice. Although not statistically significant, engagement was also negatively correlated with number of missed appointments. However, the broad category of "interpersonal environment", which included engagement, caring, and social support, did show a significant relationship ($p < 0.03$) with number of missed appointments. In an experimental study of HIV-positive men (n=42), McPherson-Baker et al. (2000) found that a 5-month medication counseling intervention led to an increase in adherence in the experimental group. The researchers identified the increased opportunity for interaction between participant and health care provider as a strength of the intervention, a hypothesis supported by Muma et al. (1995).

Further research has shown the importance of trust in the patient-provider relationship. Thom and Campbell (1997) conducted focus groups with 29 patients, asking them to recount specific incidences that had influenced their trust in their providers. Results from this study were consistent with the literature in that trust in the provider increased the likelihood of subjects' adherence to treatment recommendations. Another qualitative study, including 28 HIV-positive patients, found that patients reported that they would be less likely to trust and take ARV medications if they did not trust their provider (Roberts, 2002).

A healthy patient-provider relationship can also positively influence quality of life outcomes in those living with HIV/AIDS. A descriptive, correlational study of 707 ambulatory persons living with HIV/AIDS determined that patients who reported more engagement with their health care providers also reported significantly greater quality of life and adherence (Bakken et al., 2000).

The literature supports the assumption that a supportive patient-provider relationship can have a positive effect on health outcomes in HIV/AIDS patients.

While extensive research has been conducted examining adherence and quality of life issues in the HIV/AIDS population, few studies directly address the role of the patient-provider relationship in these areas. More research is needed in this specific area to explore the extent to which the patient-provider relationship is involved in patient outcomes. This study aims to add to the existing literature.

Methods

Design

The purpose of this study is to examine the association between engagement in the patient-provider relationship and quality of life and adherence to medication and provider advice in persons living with HIV/AIDS. This is a sub-study of an international, multi-site study examining the adequacy of a self-care symptom management model that hypothesizes relationships among person, illness representation, symptom self-care, perceived effectiveness of self-care activities, adherence, and outcomes appraisal in representing an HIV-positive sample. A cross-sectional, correlational survey design was used to answer the following research questions:

1. What is the association between engagement in the patient-provider relationship and the self-reported quality of life in persons living with HIV/AIDS?
2. What is the association between engagement in the patient-provider relationship and self-reported adherence to medication in persons living with HIV/AIDS?
3. What is the association between engagement in the patient-provider relationship and self-reported adherence to provider advice in persons living with HIV/AIDS?

Sample

The target population for this study was adult males and females living with HIV/AIDS in the greater Columbus, Ohio area. A convenience sample was obtained from The Ohio State University Infectious Diseases Outpatient Clinic and the Children's Hospital Family AIDS Clinic and Educational Services. Inclusion criteria were: 1) male or female, 18 years of age and older; 2) English speaking; 3) HIV-positive; 4) able and willing to provide informed consent. There were no exclusion criteria related to ethnicity, gender, severity of disease, or presence of other co-morbidities other than not meeting inclusion criteria.

Procedure

The study was approved by The Ohio State University Behavioral and Social Sciences Institutional Review Board (IRB) and the Children's Hospital IRB for the protection of human subjects.

To recruit for the study, the researcher placed a flyer in the OSU Infectious Diseases outpatient clinic and Children's Hospital, inviting patients to participate in the study. The researcher visited the clinic weekly to meet with potential participants during their regular clinic appointment. During the meeting, the purpose of the study was explained, at which point, if the subject wished to participate and met the inclusion criteria, informed consent was obtained. The Rapid Estimate of Adult Literacy in Medicine (REALM) was used to assess the subject's ability to read common medical words and to determine the subject's ability to complete the questionnaire independently. Subjects unable to read at the sixth grade level received assistance from the researcher. Upon completion of the questionnaire, which contained no identifying information, subjects placed the survey in a sealed envelope and received $20 as a thank-you for their time. Informed consent forms were locked in a file drawer separate from completed surveys so that there was no way to identify participants with their surveys.

Instruments

The 35-page survey contains several instruments measuring various aspects of HIV symptom management. The larger study will examine all of the data collected; however, this study only analyzed subjects' responses to demographic/individual characteristics, patient-provider relationship, perceived quality of life, and adherence to medications. Table 1 provides an overview of this study's variables and the instruments used to measure each.

Demographic questionnaire. A set of demographic questions, including age, gender, race/ethnicity, length of time known to be HIV-positive, and presence of AIDS diagnosis were used to describe the sample. Age refers to the number of years of life. Gender refers to subjects' identification as either male or female. Race/ethnicity refers to membership in a self-

identified ethnic group. Length of time known to be HIV-positive refers to the number of years, or months, subjects have known about their HIV-positive status. AIDS diagnosis refers to whether or not subjects have ever been diagnosed with AIDS.

Engagement with Health Care Provider. Engagement with health care provider is one component of the patient-provider relationship. This variable is conceptualized as "including dimensions of access to health care provider, information sharing, involvement of client in decision making and self-care activities, respect and support of the provider for the client's choices, and management of client concerns" (Bakken et al., 2000, p.190). Engagement was measured using the Engagement with Health Care Provider Scale. This is a 13-item scale requiring subjects to rate the nature of their interactions with their primary health care provider, be that person a doctor, nurse practitioner, or physician assistant. The rating is based on a four-point Likert scale, ranging from 1 "always true" to 4 "never true", with 0 representing "not applicable" added for this study. Sample questions include the extent to which subjects feel their health care provider listens to them, cares about them, involves them in decisions, and respects them. Total scores can range from 0 to 52, with lower scores indicating more engagement with health care provider.

The scale was developed by Bakken et al. (2000) for initial use in a descriptive study (n=707) exploring the relationship between HIV/AIDS patients' perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen. The scale was submitted to a principal components factor analysis with Varimax rotation. A one-factor solution emerged with an Eigenvalue of 8.6 and 66.5% of the variance explained. Cronbach's alpha reliability estimate was 0.96.

Advice and Instruction. Adherence to advice and instruction refers to how well subjects comply with provider advice and was measured using the Advice and Instruction scale. This 5-item scale asks subjects if they have difficulty following their health care provider's advice, have followed advice, the importance of the advice, what the health care provider expects, and what

family/friends think about the advice. Scores on each question range from 1 to 4 for a total score range of 5 to 20. Two items, difficulty following advice and importance of advice, are reversed scored, so that the lower the total score for all items, the more adherent the subject is to medical advice.

Holzemer et al. (1999) developed the scale for use in a study examining the relationships between the five dimensions of a health-related quality of life model and self-reported adherence to medication, provider advice, and medical appointments in people living with HIV. The instrument was tested for the study in a convenience sample (*n*=420) of HIV-infected men and women at various sites in seven cities across the United States to enhance external validity. Cronbach's alpha reliability estimate was modest at 0.61, but determined to be adequate.

HIV/AIDS Targeted- Quality of Life (HAT-QoL). Quality of life encompasses numerous facets of life and has been defined as a "multidimensional construct" (Vogl et al., 1999, p.254). It was measured using the HAT-QoL instrument. This 42-item HIV-specific instrument assesses the following nine dimensions of quality of life: overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust, and sexual function. All dimensions are scored so that the final dimension score is transformed to a linear 0 to 100 scale. However, for this study, the raw final score was used to facilitate data analysis. Therefore, scores could range from 0 to 136, where higher scores indicate better functioning.

The instrument was developed by Holmes and Shea (1998). Group discussions from a sample of HIV-positive individuals (*n*=42) were used to generate initial item content for the instrument. Results from this first study yielded a 76-item instrument. A second, cross-sectional study was then performed with HIV-positive individuals (*n*=201) to identify dimensions and reduce the number of items. Cronbach's alpha reliability estimate was = 0.70 for all dimensions, except HIV mastery (0.57), medication concerns (0.51), and sexual function (0.56). Multitrait/multiitem assessment indicated correct correlations (= 91%) for eight of the nine

dimensions. HIV mastery revealed a lower success rate of 79%. Construct validity was determined through various self-reported HIV disease markers and self-reported sociodemographic variables.

AIDS Clinical Trials Group (ACTG) Reasons for Non-Adherence to Medications. According to Holzemer et al. (1999), medication adherence, and consequently, non-adherence, is defined as it is measured. Non-adherence was measured using the *ACTG Reasons for Non-Adherence to Medications*, which is a 15-item checklist of reasons patients may not take medications as prescribed. The more items that are checked, the more likely an individual is to be non-adherent to their medication regimen.

Data Analyses

The sample is described using univariate descriptive statistics including frequency, percentage, mean, range, and standard deviation as appropriate.

Pearson's correlations were used to analyze the association between engagement in the patient-provider relationship and perceived quality of life, medication adherence, and adherence to provider advice.

Results

Sample

A total of 57 subjects were recruited for the study. Ages ranged from 20 to 65 (mean=40.4, SD=9.7) years and females comprised 28% of the sample. The ethnicity of the sample was African American, 35%; Hispanic/Latino, 2%; Native American, 3%; white, 58%; and Other, 2%. Average length of HIV diagnosis was 10 years (SD=5.7). Thirty-nine percent of the subjects reported having been diagnosed with AIDS. Socio-demographic data are summarized in Table 2.

Engagement with Health Care Provider

The mean score was 17.9 (SD=8.4) with a range of 0 to 43, lower scores indicating more engagement. Primary health care provider type of the sample was doctor, 93%; and nurse practitioner, 7%. Table 3 provides scores from individual constructs and their respective measures.

Relationship Between Engagement with Health Care Provider and Quality of Life

The mean score on the HAT-QoL scale was 56.9 (SD=21.1) with scores ranging from 28 to 119. Higher scores indicate better functioning and quality of life. Improved quality of life was significantly related to engagement with health care provider (p=0.013). Correlations are presented in Table 4.

Relationship Between Engagement with Health Care Provider and Adherence to Medications

Scores on the 0 to15 medication adherence checklist ranged from 0 to 9, with a mean of 1.5 (SD=1.9). Lower scores indicate better adherence. While positively correlated, there was no evidence of a statistically significant relationship between engagement and adherence to medication.

Relationship Between Engagement with Health Care Provider and Adherence to Provider Advice

The mean score on the advice and instruction scale was 6.8 (SD=1.4) with a range of 5 to 11, lower scores indicating more adherence. Comparisons revealed a significant relationship between engagement and adherence to provider advice (p=0.001).

Discussion

In this study of outpatient HIV/AIDS patients, participants who reported a higher level of engagement and quality of life, were more likely to be adherent to their provider's advice. Significant relationships between engagement in the patient-provider relationship and quality of life and adherence to provider advice were found.

These results support existing literature suggesting a positive relationship between engagement with health care provider and adherence. Notably, Bakken et al. (2000) conducted a similar study examining the same variables. Results of that study, too, yielded a significant relationship between engagement and adherence to advice and instruction ($p<0.001$) in a much larger sample ($n=707$). Further, clients in the sample reporting higher scores on the quality of life measure also reported more engagement with health care provider, consistent with the findings of this study.

Few previous studies have specifically examined the relationship between engagement and quality of life. Respondents in this study reporting high levels of engagement also reported improved quality of life. While a standardized measurement to assess quality of life is not available, an interplay of psychological, social, and physical factors is involved. Findings of this study support the influence of social factors, specifically the role of the patient-provider relationship, in quality of life within this population.

Research examining adherence to therapeutic regimen among persons with HIV/AIDS has been extensive, given its direct relationship to disease progression (Holzemer et al., 1999; McPherson-Baker et al, 2000; Blaschke, 1997). Correlates of non-adherence identified by researchers include the presence of distressing symptoms (Fontaine et al., 1999), treatment-related symptoms (Melbourne, et al., 1998), and poor quality of life markers (Holzemer et al., 1999). Results of this study identify an association, although not statistically significant, between engagement and adherence to medication. The instrument used to measure adherence in this study could have influenced this finding, in that it asks respondents potential reasons they may

not take their medication; consequently, it is not measuring adherence directly, but reasons for non-adherence.

A positive relationship between engagement and adherence to provider advice was also demonstrated in this study. Thom and Campbell (1997) reported that patients who trusted their health care provider were more likely to follow treatment recommendations.

Implications

Findings of this study can be used clinically to improve the interaction between clients with HIV/AIDS and their health care providers. The results suggest a strong link between this interaction and patient outcomes of quality of life and adherence to therapeutic regimens. Awareness of this association should encourage the provider to foster a caring, therapeutic relationship with clients to promote positive outcomes. Nurses, particularly, are in an optimal position to foster such a therapeutic relationship, as they are intimately involved in patient care. Indeed, a study of HIV/AIDS patients found that having a primary nurse was a significant predictor of client satisfaction with care (Stone, Weissman, & Cleary, 1995).

Limitations

Limitations of this study included those inherent in the research design used. For example, inaccuracies due to poor subject recall can be expected in a self-report design such as this. Furthermore, the design poses a potential threat to both internal and external validity. Because a convenience sample is being used, respondents are not randomly selected, and, therefore may not be representative of all members of the target population. However, demographic characteristics of the sample have been reported to provide a better picture of the specific population to whom the results are generalizable. Results should be examined in this context.

Conclusion

A positive relationship was demonstrated between patient-provider engagement and quality of life and adherence behavior among participants in this study. These findings are consistent with existing literature and have implications for the development of clinical strategies to improve the nature of the patient-provider relationships within the HIV/AIDS population. Understanding that this relationship is associated with patient outcomes, such as quality of life and adherence, should encourage health care providers to be more conscience and deliberate in their interactions with clients to ensure this interaction is perceived positively by the clients. Nurses, especially, must understand the holistic nature of the disease in order to realize that their therapeutic relationship, in addition to medical interventions, can influence disease progression in this population.

Care of the HIV/AIDS client is multi-faceted, encompassing issues of disease, financial, psychological, and social status. Results of this study suggest the need for strategies that foster a healthy patient-provider relationship to enhance quality of life and adherence to treatment among persons living with HIV/AIDS. Further research is needed in this area to determine interventions that will be most successful in reaching these aims.

References

Bakken, S., Holzemer, W.L., Brown, M., Powell-Cope, G.M., Turner, J.G., Inouye, J., et al. (2000). Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care and STDs, 14*(4), 189-197.

Blaschke, T.F. (1997). Noncompliance and resistance to protease inhibitors. Fourth Conference on Retroviruses and Opportunistic Infections.

Burr, C.K. (1996). Supporting the helpers. *Nursing Clinics of North America, 31,* 243-251.

Centers for Disease Control and Prevention (n.d.). *A Glance at the HIV Epidemic.* Retrieved March 10, 2003, from www.cdc.gov/nchstp/od/news/At-a-Glance.pdf

Chesney, M.A. (1997). New antiretroviral therapies: adherence challenges and strategies. Presented at Evolving HIV Treatments: Advances and Challenges of Adherence, 37th ICAAC Symposium, Toronto, Canada.

Chow, R., Chin, T., Fong, I.W. & Bendayan, R. (1993). Medication use patterns in HIV-positive patients. *Cancer Journal of Hospital Pharmacy, 46,* 171-175.

Fontaine, A., Larue, F. & Lassauniere, J. (1999). Physicians' recognition of the symptoms experienced by HIV patients: How reliable? *Journal of Pain and Symptom Management, 18*(4), 263-270.

Frank, H. (1986). AIDS: The responsibility of health care workers to assume some degree of some personal risk. *The Western Journal of Medicine, 144,* 363-364.

Gerbert, B., Macguire, B., Badner, V., Altman D. & Stone, G. (1988). Why fear persists: Health care professionals and AIDS. *Journal of the American Medical Association, 260,* 3481-3483.

Holmes, W.C. & Shea, J.A. (1998). A new HIV/AIDS-targeted quality of life (HAT-QoL) instrument- Development, reliability, and validity. *Medical Care, 36*(2), 138-154.

Holzemer, W.L., Corless, I.G., Nokes, K.M., Turner, J.G., Brown, M., Powell-Cope, G.M., et al. (1999). Predictors of self-reported adherence in persons living with HIV disease. *AIDS Patient Care and STDs, 13*(3), 185-197.

Holzemer, W.L., Spicer, J.G., Wilson, H.S., Kemppainen, J.K. & Coleman, C. (1998). Validation of the quality of life scale: Living with HIV. *Journal of Advanced Nursing, 28*(3), 622-630.

Ickovics, J.R. & Meisler, A.W. (1997). Adherence in AIDS clinical trials: A framework for clinical research and clinical care. *Journal of Clinical Epidemiology, 50,* 385-391.

Israelski, D., Eversley, R., Janjua, S., & Smith, S. (1998). Race, HIV symptoms, recovery from drug abuse, and appointment adherence are associated with quality of life (QOL) among HIV infected women. *12th World AIDS Conference*, Geneva, June 28-July 3, 1998.

Kemppainen, J.K., O'Brien, L. & Corpuz, B. (1998). The behaviors of AIDS patients toward their nurses. *International Journal of Nursing Studies, 35,* 330-338.

Kelly, J.A., St. Lawrence, J.S., Hood, H.V., Smith, S. & Cook, D.J. (1988). Nurses' attitudes toward AIDS. *The Journal of Continuing Education in Nursing, 19*(2), 78-83.

McPherson-Baker, S., Malow, R.M., Penedo, F., Jones, D.L., Schneiderman, N., & Klimas, N.G. (2000). Enhancing adherence to combination antiretroviral therapy in non-adherent HIV-positive men. *AIDS Patient Care and STDs, 12*(4), 399-404.

Melbourne, K., Abbaticola, M., Rana K. & Fisher, A. (1998). Tolerability and body composition of HIV-infected individuals on retonavir-containing regimens. Abstracts of the 38th ICAAC, San Diego, California.

Muma, R.D., Ross, M.W., Parcel, G.S. & Pollard, R.B. (1995). Zidovudine adherence among individuals with HIV infection. *AIDS Care, 7,* 439-447.

Pearson, S.D. & Raeke, L.H. (2000). Patients' trust in physicians: Many theories, few measures, and little data. *Journal of General Internal Medicine, 7,* 509-513.

Peate, I. (1995). A question of prejudices. Stigma, homosexuality and HIV/AIDS. *Professional Nurse, 10,* 380-383.

Reynolds, N.R., Neidig, J.L. & Brashers, D.E. (1999). Patient appraisal of mandarin-orange didanosine: Implications for adherence and well-being. *Journal of the Association of Nurses in AIDS Care, 10,* 35-42.

Roberts, K.J. (2002). Physician-patient relationships, patient satisfaction, and antiretroviral medication adherence among HIV-infected adults attending a public health clinic. *AIDS Patient Care and STDs, 16*(1), 43-50.

Robinson, N. (1998). People with HIV/AIDS: who cares? *Journal of Advanced Nursing, 28*(4), 771-778.

Rose, L. (1994). Homophobia among doctors. *British Medical Journal, 307,* 586-587.

Singh, N., Squier, C., Sivek, C., Wagener, M., Nguyen, M.HJ. & Yu, V.L. (1996). Determinants of compliance with antiretroviral therapy in patients with human immunodeficiency virus: Prospective assessment with implications for enhancing compliance. *AIDS Care, 8,* 261-269.

Stone, V.E., Weissman, J.S., & Cleary, P.D. (1995). Satisfaction with ambulatory care of persons with AIDS: Predictors of patient ratings of quality. *Journal of General Internal Medicine, 10,* 239-245.

Taylor, I. & Robertson, A. (1994). The health needs of gay men: a discussion of the literature and implications for nursing. *Journal of Advanced Nursing, 20,* 560-566.

Thom, D.H., Campbell, B. (1997). Patient-physician trust: an exploratory study. *Journal of Family Practice, 44,* 169-176.

van Wissen, K. & Woodman, K. (1994). Nurses' attitudes and concerns to HIV/AIDS: A focus group approach. *Journal of Advanced Nursing, 20,* 1141-1147.

Vogl, D., Rosenfeld, B., Breitbart, W., Thaler, H., Passik, S., McDonald, M., et al. (1999). Symptom prevalence, characteristics, and distress in AIDS outpatients. *Journal of Pain and Symptom Management, 18*(4), 253-262.

Wachtel, T., Piette, J., Mor, V., Stein, M., Fleishman, J. & Carpenter, J. (1992). Quality of life in persons with human immunodeficiency virus infection: measurement by the medical outcomes study instrument. *Annals of Internal Medicine, 16,* 129-137.

Wilson, H.S., Hutchinson, S.A. & Holzemer, W.L. (1997). Salvaging quality of life in ethnically diverse patients with advanced HIV/AIDS. *Qualitative Health Research, 7*(1), 75-97.

Appendix

Table 1.

Overview of Study Variables and Instruments

Variable and Instruments
Engagement with health care provider
Engagement with Health Care Provider Scale
Demographic characteristics
Demographic questionnaire
Age
Gender
Race/ethnicity
AIDS diagnosis
Length of time known HIV-positive
Quality of life
HIV/AIDS Targeted Quality of Life Scale
Overall function
Life satisfaction
Health worries
Financial worries
Medication worries
HIV mastery
Disclosure worries
Provider trust
Sexual function
Adherence
Advice and Instruction scale
ACTG Reasons for Non-Adherence to Medication

Table 2.

*Sociodemographic Characteristics of HIV/AIDS Patients in Central Ohio, 2003 (*n=*57)*

Variable		Frequency	Percent
Gender	Male	40	70.2
	Female	16	28.1
	Transgender	1	1.8
Race/Ethnicity	African-American	20	35.1
	Hispanic/Latino	1	1.8
	Native American	2	3.5
	White	33	57.9
	Other	1	1.8
AIDS diagnosis		22	38.6

Variable	Range	Mean	SD
Age (years)	20-65	40.4	9.7
Length of HIV diagnosis (years)	1-19	10	5.7

Table 3.

*Scores on Engagement, Quality of Life, Medication Adherence, and Adherence to Provider Advice of HIV/AIDS Patients in Central Ohio, 2003 (*n=*57)*

Construct	Instrument	Number of Items	Range	Mean	SD
Engagement	Engagement with Health Care Provider	13	0-43[a]	17.9	8.4
Quality of Life	HAT-QoL	42	28-119[b]	56.9	21.1
Medication Adherence	ACTG Reasons for Non-Adherence to Medications	15	0-9[c]	1.5	1.9
Adherence to Provider Advice	Advice and Instruction	5	5-11[c]	6.8	1.4

[a] Lower scores indicate more engagement
[b] Higher scores indicate improved quality of life
[c] Lower scores indicate better adherence

Table 4.

*Correlations Between Engagement, Quality of Life, and Adherence Among HIV/AIDS Patients in Central Ohio, 2003 (*n*=57)*

	Engagement with Health Care Provider
Hat-QOL	.329*
ACTG Reasons for Non-Adherence to Medications	.272
Advice and Instruction	.417**

* Correlation is significant at the 0.05 level
** Correlation is significant at the 0.01 level